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# Patient safety in community dementia services: what can we learn from the experiences of caregivers and healthcare professionals?

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## Abstract

**Objectives:** this study aims to explore how patient safety in community dementia services is understood by caregivers, and healthcare professionals.

**Methods:** cross-sectional analysis of guided one-to-one interviews with 10 caregivers, and 10 healthcare professionals.

**Results:** caregivers and healthcare professionals identified a range of issues including medication errors, mis-communication between professionals, unclear service pathways and the effects of stress on caregivers' behaviour. Caregivers and professionals differed in their attitudes to balancing safety with patient autonomy and who is responsible for managing safety.

**Conclusions:** this article helps to define the nature of safety issues in the context of community care for people with dementia. In contrast to hospital medicine, where the ideal treatment world is safe with all risks managed or minimised, in dementia some risks are actively taken in the interests of promoting autonomy. Caregivers' views differ from those of health professionals but both parties see potential for collaborative working to manage risk in this context, balancing the promotion of autonomy with the minimisation of potential harm.

**Keywords:** dementia services, patient safety, caregivers, risk, qualitative, older people

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## Introduction

Patient safety is an increasingly important indicator of service quality; this is recognised in the Francis Report [1] and subsequent Berwick Report [2], which concluded that 'patient safety improves when patients are more involved in their care and have more control'.

Patient safety research has focused on patients in hospital where there is evidence that the active participation of individual inpatients in their clinical care can reduce the risk of adverse events [3]. Hospital based harm of patients with dementia has also been studied to a small extent [4] as have adverse events in general community healthcare services [5, 6] but not specifically in the care of people with dementia. Views and experiences of patients and caregivers have not been researched.

Healthcare is increasingly being delivered outside hospital, and the new risks this poses are still being determined [7]. In community care, patients and carers play a more active role and take on many responsibilities that are the prerogative of professionals in hospital [8]. Identifying unintended injury may be harder in the community than in hospital, but could be a potential role for caregivers.

When caring for a person with dementia, the pursuit of the eradication of harm may not always be in the patient's best interests and some degree of risk may be necessary to maximise patient autonomy and wellbeing. The term 'dignity of risk' is used in Australia to describe this concept. In the United Kingdom, the dignity of older people has been conceptualised as encompassing dignity of identity, human rights, and autonomy [9]. The autonomy aspect of dignity in dementia

care has been examined further with regards to quality of life decisions [10], but not explicitly considering risk-taking as a means of maximising autonomy and thus dignity.

The aim of this exploratory study is to better define and understand safety in the context of community healthcare of people with dementia to help to optimise patient and caregiver experience in the future. We believe that involving caregivers and attempting to involve patients in this study is a first step towards amplifying their voice on this important issue.

## Methods

### Study design

A cross-sectional qualitative study using guided interviews to identify and compare patient safety concerns in community dementia services reported by caregivers and healthcare professionals.

Ethical approval was granted (South Wales REC 14/WA/0102). Participants were recruited through community mental health teams, memory clinics and the local research network. Participants were purposively selected to ensure that a maximum range of experiences were explored.

The original protocol included interviews with 10 people with dementia. However, recruitment of people able to consent to participation was difficult and those recruited were unable to provide usable data.

For caregivers, inclusion criteria included:

- Aged 18 years or above.
- Currently caring for a close friend or relative with dementia who has been under the care of community mental health team and/or memory clinic in the last year.
- Caregiving involves an average of two or more in-person contacts per week, over at least a 6-month period.

For healthcare professionals, inclusion criteria included:

- Clinician with professional registration involved in provision of community mental health and/or memory clinic services to people with dementia.

Participants were contacted by telephone by author 1 and sent a brief information sheet about the study. There was an excess of participants referred to the study, so only those purposively selected were contacted; all of these participants completed the study. Author 1 conducted qualitative in-depth one-to-one interviews lasting up to one hour which were informed by a pre-designed topic guide and audio recorded (Supplementary data, Appendices 1 and 2, available in *Age and Ageing* online). Verbatim transcripts were coded using structural frameworks based on the key research questions (Supplementary data, Appendix 3, available in *Age and Ageing* online). Frameworks were subsequently populated by inductive themes for both of the participant groups. Key extracts of supporting text were linked to each theme [11] and subsequently condensed and confirmed by checking of random transcripts during the first and final cycle of analysis by authors 3 and 1. Data

analysis was managed using NVIVO version 9 ([www.qsrinternational.com](http://www.qsrinternational.com), 16 November 2016, date last accessed).

## Results

### Participant characteristics

Participant characteristics are summarised in Table 1.

### Themes

Three key themes and 11 subthemes emerged.

#### 1 What safety means in the context of community dementia services

All caregivers were able to identify actual and potential safety problems although few had formally reported them. Some were concerned that people with dementia would not be able to report them.

Healthcare professionals were well aware of the need for risk assessments, but noted such assessments' limitations.

*Well, you should do a risk assessment on every patient you see... but you never know all the risks.* HCP7.

#### 2 Where safety failures lie

Seven subthemes are summarised in Table 2.

Systemic safety failures were frequently identified, with almost unanimous dissatisfaction with the complexity of the care system. Many caregivers reported not knowing who to approach for advice and both caregivers and professionals were aware of poor communication between professionals, leading to unsafe care.

'Person-centred care' was seen as a gold standard by most participants. Healthcare professionals believed that in person-centred care autonomy and quality of life must be balanced and some risks accepted. Some noted that a lack of autonomy may make a patient feel unsafe.

Most professionals and some caregivers had witnessed safety problems with administering medication to people

Table 1. Characteristics of participants.

	Caregivers ( <i>n</i> = 10)	Healthcare professionals ( <i>n</i> = 10)
Gender	Male: 5 Female: 5	Male: 2 Female: 8
Habitation status	Living alone: 2 Living with person with dementia: 8	n/a
Interview status	Interviewed alone: 8 Interviewed with person with dementia: 2	Interviewed alone: 10
Relationship/role	Spouse of person with dementia: 8 Son or daughter of person with dementia: 2	Psychiatrist: 2 Occupational therapist: 2 Nurse: 2 Social worker: 1 Psychologist: 1 Pharmacist: 1 General practitioner: 1

Table 2. Where safety failures lie—subthemes.

Subtheme	Quotation
Unclear pathway through services (lack of guidance and information)	<i>I suppose it was sometimes a bit muddled as to...who you're actually supposed to be communicating with.</i> CG1
Services not coherent (discontinuity and poor communication)	<i>There is not enough joined up thinking between professionals...I think the onus is often on the person or the carer.</i> HCP8.
Services not person-centred	<i>It should be based on the needs of the patient, but it's not like that...You're pushed to go for the cheapest option...</i> HCP5.
Poor medication management	<i>...they come in a different form, the tablets.. he says "no this isn't my tablet" because he doesn't recognise it...</i> CG5.
Caregiver stress and burn out	<i>You can snap...you can get to the stage when you really are at your wits' end...when K was being particularly difficult I have slapped her.</i> CG1
Lack of engagement	<i>There's a minority of people who don't have an active relative or friend. It's very difficult to help those people access things when they need it.</i> HCP6.
Safety issues specific to dementia (getting lost and violence)	<i>I had one case who...was really quite aggressive to his wife...he was clearly quite dangerous.</i> HCP4.

with dementia. Caregivers spoke of the impact of frequent changes of medication formulation on the patient’s compliance. Some caregivers reported making changes to the dosing of prescribed medication or administering medication covertly without medical advice. Professionals were concerned by such practices.

All caregivers reported stress while all professionals described a link between poor caregiver physical and mental health and safety risks to both parties. Other safety risks specific to dementia included getting lost, violence and poor engagement with professionals, particularly when there is no active family carer.

3 How safety failures are reported and managed

Most professionals mentioned the local formal safeguarding process (the procedures by which agencies collaborate to protect vulnerable adults) [12].

3a: Barriers to raising concerns

A common theme was the caregivers’ wish not to trouble professionals or to make a fuss. Many were worried that their family member might receive substandard care if they raised a concern. However, professionals believed that people who complain receive better care.

*I was really worried about saying anything to them because she’s social services funded and they’d say “oh well, if you don’t like it find her somewhere else”. CG3.*

3b: Differing views on who is in control

Both professionals and caregivers felt it was their role to manage the patient’s care, including managing safety and balancing risk with autonomy; both agreed that collaboration with the other should be possible. Professionals recognised that patients and caregivers vary in their ability to raise concerns and some did not wish to burden caregivers with organisational responsibilities.

*There are some patients with years of insight into their illness and the risks...and the same is for carers...but it can’t be expected that patients take ownership of their risks.* HCP7.

3c: Healthcare professionals’ and caregivers’ views on the balance of safety and autonomy

Caregivers took a more pragmatic view of maintaining patient safety at odds with their perception of professionals’ reliance on bureaucracy. Professionals talked about the struggle to balance optimisation of quality of life of the patient with the elimination of risks.

*We requested the carers be allowed to give my mum...medication..., covertly. The agency wouldn’t do that...they quoted some European legislation.* CG2.

Discussion

This was a small study based in a single healthcare trust and further research with a larger sample would be required to reveal if our findings held salience beyond this setting.

The most notable finding was that of the difference between professionals’ and caregivers’ conceptualisation of safety in this context, how the tension between autonomy and harm should be managed, and who should bear the responsibility of risk management.

Some of the themes mirror the findings of the United Kingdom Alzheimer’s Society’s report into challenges facing caregivers [13], in particular mis-communication between professionals and problems involving medication management. Surprisingly, although it is known from previous studies that caregiver stress is associated with abusive behaviours [14], professionals did not raise this as a safety concern. A previous study found that caregivers take on increasing responsibility for decision making as cognition declines [15], which resonates with our findings.

Initially, caregivers interviewed often did not feel qualified to be discussing safety in healthcare, but they became more engaged through the interview. Raising awareness of safety in healthcare and proactively supporting caregivers to identify and report concerns might, therefore, empower them to act in the future in collaboration with healthcare professionals. There are a number of potential interventions that could be piloted immediately, including systems for caregivers to identify and report safety risks, and improved methods of medication management.

## Key points

- This qualitative study compares the experiences of caregivers with those of health professionals in community dementia services
- Caregivers and professionals have different attitudes to balancing safety and autonomy
- Caregivers and healthcare professionals identify a range of safety issues
- People with dementia were unable to identify unsafe or potentially unsafe aspects of healthcare
- There is a need for systems for identification and reporting of safety risks in community dementia care

## Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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## Glossary

CG, caregiver; HCP, healthcare professional.

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